
Defaulting to Data Use

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Is there an obligation to participate?

Medical knowledge is a public good.

- One person's using it does not diminish its value.
- We cannot prevent people from using it.

We all need medical research; it is not optional.

- Quality healthcare isn't possible without research.
- We all need quality healthcare.

We have a *limited* obligation to participate.

Should data use be obligatory?

Record-based research poses few *new* risks.

- Most privacy/security risks exist already.
- There is no direct sacrifice or burden on patients.
- Specific preferences about research are rare.

If there is an obligation to participate, this is perhaps the easiest case.

Why not make data use obligatory?

People seem to want to be asked.

- About 75% in a recent study had a preference for consent; others have been similar.
- They were sensitive to practical considerations, and many find broad consent acceptable.

There are implications for trust and integrity.

There are not data to justify conscription.

We should explore alternatives

Limited obligation grounds the use of default strategies (e.g. opt-out) and positive framing.

Consent serves very little protective function.

Many models affect decisions while still affording control.

There are multiple ways to promote transparency and trust.